

PSYCHO-SOCIAL ASPECTS OF LEPROSY¹

Oliver W. Hasselblad, M.D.²

A smog of ignorance, fear, myth, and superstition surrounds the problem of leprosy. This often reduces the chances for early diagnosis and treatment of the disease, and frequently affects the patient's own mental attitude so as to sharply restrict his chances for ever resuming a useful, creative life. The present article describes these psycho-social implications and cites a number of ways in which their adverse consequences can on occasion be diminished or overcome.

Introduction

At the outset, two comments may be made about the pscho-social aspects of leprosy: First, no other disease is so clouded by myth and inaccurate information; second, no aspect of this disease has had less scientific study applied, yet needs it more.

It is safe to assume that should medical research come up with a safe, proven, and effective treatment for leprosy that would cure it within six weeks in a majority of cases, the problem of significantly reducing the incidence of the disease would remain for decades. Likewise, should a leprosy vaccine become a universal tool in our hands, as certain in its effect as smallpox vaccine, for example, it would take a great many years for the full impact of this sure, safe method of prevention to be felt.

One reason for these discouraging estimates is the straightforward problem of logistics in delivering the services suddenly placed at our disposal. But another reason of equal importance is the stifling smog of ignorance, fear, myth, and superstition that creates a psycho-social barrier—a barrier which prevents an early diagnosis of cases in patients with der-

matological lesions before the onset of neuropathies and subsequent deformities. Like the downward pull of gravity, we know the barrier is there. The trained scientist can explain the reasons for it, but no one knows how to surmount it.

This is the stigma that clings to leprosy. There are many theories, some of them valid but few scientifically proven, to account for the psychopathic attitudes of the well community and also of many afflicted patients. No one knows how to bring about a significant reversal of this unreasonable behavior. All we have is a mass of disorganized opinions, based upon fragmented knowledge and conditioned by limited experience. The number of documented studies on behavioral attitudes of the community and of the patient, carried out by trained, competent, experienced social scientists familiar with the cultural milieu of a local situation, is indeed limited.

Yet it is safe to conclude that there is no greater obstacle to application of the effective therapeutic armamentarium at our disposal. This is the very matter which will determine success or failure in early case-finding, case-holding, and prevention of disabling deformity: the psycho-social elements governing attitudes and human behavior on the part of patient, family, and community.

Even if we do not have accurate information as to *why* certain chain reactions are set in motion when leprosy is diagnosed, we do know a great deal about *what* happens to large numbers of patients. We must be certain we are dealing with the *whole* person, not just

¹Paper presented at the PAHO course on Recent Advances in the Diagnosis, Treatment, and Control of Leprosy provided for officials of the countries and other political units of the Caribbean area, in Paramaribo, Surinam, on 20-24 May 1974. Also appearing in Spanish in the *Boletín de la Oficina Sanitaria Panamericana*, Volume LXXVIII, 1975.

²Medical Consultant, American Leprosy Missions, Inc., 297 Park Avenue South, New York, New York, U.S.A.

a skin lesion or a paralyzed nerve. Accordingly, we must seek the *whole causes* of what may happen to patients, and then finally *whole solutions*.

Let us then forego the temptation to repeat all the old, tired, and worn shibboleths that seek to explain why leprosy patients have unjust social penalties applied to them. Let us not speak of the past, but of what today continues to happen to large numbers of patients, admittedly influenced by cultural determinants that are never universally applicable.

The Patient's Changed Identity

When a person contracts leprosy, his identity changes in very real ways. We speak of a person having two identities: his self-identity and his social identity. *Self-identity* refers to a person's concept and belief about himself, the way he conceives his worth, his relationship with others, his capacities, weaknesses, and achievements—what he perceives his place in society to be. *Social identity* refers to the labelling of a person by others, based on information about him that is available to them.

A striking element in the change of identity which the leprosy patient is likely to undergo is that his new identity is far-removed from actual fact. That is, what he thinks about himself, or his concept of what society thinks of him, is not based upon the truth.

We speak of the "stigma" attached to leprosy and use the word to express the inexplicable reasons for which a patient is shunned, both by himself and society, even to the point of self-loathing. For leprosy as a disease has the peculiar distinction of being, in the public mind, the worst disaster that can befall a person. As explained by Gussow, Knight, and Miller in an article entitled "A Theory of Leprosy Stigma and Professionalization of the Patient Role: Adaptation to a Chronic and Uncertain Disease," leprosy presents the image of "total maximal physical illness" similar to the idea of totally losing one's mind as expres-

sed by the terms "lunacy" and "insanity." For the patient with leprosy the calamity-charged term is "leper." Gussow points out that the maximum negative social and emotional responses are elicited by a condition which results, not in death, but in severe bodily deterioration.

The Patient's Psychological Options

The combined elements of high, repulsive visibility and mysterious, seemingly uncontrollable onset and progression elicit a psychological reaction of diminished self-esteem. The patient is uncertain how to view himself, how he will be viewed by others. Normally the diagnosis of any illness activates feelings of guilt about real or supposed wrongdoings, for which the illness is an imagined punishment. These guilt feelings can generally be disposed of when confronted by rational explanations for the condition, and by visible improvement with treatment.

The leprosy patient characteristically reacts to his guilt feelings by denying the presence of the disease. By the time the condition forces him to seek treatment, it has often progressed to a point where improvement is not readily forthcoming. Faced with the reality of his illness, the patient can then take one of two possible courses: he can continue to conceal his condition, or he can reveal it.

We now begin to see more clearly the great importance of psycho-social factors affecting the patient and all to whom he is related, and their implications for early diagnosis, early regular treatment, case-holding, and prevention of disabling deformities.

The patient's decision—whether or not to conceal his condition—depends largely on the characteristics of his personality before the disease was diagnosed. Naturally his cultural, economic, educational and vocational status—the stability of his position within family, home, and community, will also be crucial. Within this context he will be influenced by any fictions about the disease with which he

is familiar and which predominate in his community; and his attitude toward the disease will be very greatly influenced by whoever makes the diagnosis, by where it is made, and by the supportive forces brought to bear from that moment on.

Concealment

Should the patient decide to conceal his disease, he can either (1) continue as normal, engaging in those behavior patterns consistent with his social identity, or (2) activate new behavior patterns which he now permits himself, based on his self-identity as a person with a stigmatized condition. If he follows the latter path, he will have to give up certain behavior patterns which would normally be expected or permitted. In any case, he is now facing a new situation in which he possesses a double and disjunctive identity. His secret knowledge of himself, and therefore his self-identity, are at odds with his social identity.

Leprosy institutions throughout the world are full of patients who have so altered their self-identity that they can no longer live in society. To themselves they are "lepers." They are unable to build up a self-identity which would reestablish their feelings of self-respect and integrity. Rejecting themselves, they seek a rejecting environment in order to have a realistic basis for their hostilities and depressions. As Dr. Gussow has said,

Most patients elect to conceal their leprosy identity from society. Many take up permanent residence at the hospital, living, working, sometimes marrying; they protect themselves by "colonizing."³

The patient's decision to conceal his illness, and the resultant widening gap between his self-identity and social identity, thus produces a sense of isolation and rejection. This may be further enhanced by the loss of cutaneous sensation or the loss of sight by which he identifies himself in his environment. Symptoms of withdrawal, dependency, loss of abili-

ty to relate to situations rationally, thus become characteristic of his life.

Disclosure

Instead of concealing his condition, the patient may choose to reveal it. Sometimes this decision is forced by the visibility of the illness, though even then he may have the choice of withdrawing into the secluded environment of the leprosy institution. As with concealment, the decision to disclose his illness may be greatly influenced by his pre-morbid personality characteristics, and also by the attitudes toward leprosy held by his community. Psychologically the effect of disclosure is the coalescence of self-identity and social identity. The result is to decrease a disjunction which would otherwise increase.

In a society where leprosy bears opprobrious social connotations, the effect is for the patient to become self-stigmatized, an identifiable "leper" in his own mind. As Dr. Gussow points out,

A further complication in the crisis comes with the patient's realization that (1) while he has a serious condition (serious either as disease, stigma, or both), he has not changed as a person, yet (2) society would now regard him as totally different. The patient fears that his condition will engender not only a discontinuity between his past and previously expected future, but also will create an incongruity between his self-identity and his social identity. As long as he can conceal his condition, he can, within limits, engage normally in behavior open to him on the basis of a social identity in which others do not know of his stigma. But once the condition is known, the patient is faced with the problem of "building a world," to use Coffman's phrase. He has to learn what from the past must be discarded and what is salvageable, which past activities and roles will facilitate adaptation, which will not, and what new behaviors need to be added. Patients handle the discontinuity and dissonance between self and social identities in a variety of ways, and the kind and quality of their adjustment can be expected to vary according to their relation to others who hold different views about leprosy.⁴

³Z. Gussow, *et al.* (3), p.10.

⁴Z. Gussow and G.S. Tracy (2), p. 12.

Conclusions

A person's social identity is the sum total of his known behavior in relation to the mores, customs, and laws of the community in which he lives. His identity shows many facets as he relates to a wide range of groupings within the community. His vocation, financial status, education, participation in community activities, choice of friends, and so forth, identify him to his family, his friends, his acquaintances, and his society.

The effects of leprosy in altering an individual's social identity are all the more exaggerated because they are generally completely unrelated to his physical and mental capacity to continue participating in normal relationships within the community. A person may lose his job long before he exhibits any loss of ability to work. Patients are often barred from normal social intercourse within the community or family long before visible signs of the disease appear. In many societies it is enough for the patient's condition to be known; regardless of the fact that he may be confirmed as totally noninfectious and of no danger to others, he will be shunned.

In coping with this bewildering change in his normal status, the patient may withdraw. He may exert great effort to reinforce and stabilize his pre-morbid status. He may seek oblivion in another city or in an institution. Or he may accept his changed status and attempt the necessary adjustments.

When there is disability or disfigurement caused by the disease, we can expect that the patient will experience even greater alterations in his social identity. But it is well to emphasize that disability has not been conclusively identified as the basic cause of change in his social identity. Changes may arise, as has been noted, long before disabling physical manifestations have occurred.

It is not within the scope of this paper to analyze the psycho-social effects of long institutionalization on the leprosy patient. It is sufficient to observe that the patient's ability to regain a useful, creative role in community life and the chances that he will do so di-

minish in almost direct proportion to the length of time he has been institutionalized, whether for reasons of choice, community pressure, or presumed treatment of severe physical deformity. It is also safe to observe that the institutionalization of leprosy treatment, and hence of the patient, constitutes the greatest single circumstance distorting the facts of leprosy in the public mind and in the mind of the patient. It has been confirmed again and again that the vast majority of patients will inevitably prefer the risk of becoming crippled and disabled to that of losing whatever margin of vocational security can be maintained at home or in the community. Once they have left home and the community, their chances of recovering that margin of security vary in direct proportion to the length of time they have been away.

While there are no certain solutions to the psycho-social problems that arise in leprosy, many positive steps can be taken which have been proven productive. Without going into detailed reasons for mentioning particular measures, a few of them can be readily identified as follows:

- 1) During the process of diagnosis, the importance of assisting the patient to maintain both his self-identity and social identity cannot be overemphasized. Where the diagnosis is made—for example, in a general skin clinic as opposed to the outpatient department of a leprosarium—is important. The attitudes of the person making the diagnosis, of all medical and paramedical personnel who in any way deal with the patient, and, equally important, the attitudes of his family in the first hours and days after diagnosis, may permanently affect the decisions to be made. Those decisions in turn will affect the success or failure of the patient's whole future course of treatment.

- 2) A public health approach to the management of leprosy that permits a patient to remain at home while under treatment will hold all family and community relationships intact more than any other single factor. When complications arise requiring hospitaliza-

tion, it is preferable that the patient be cared for at a general hospital and for the shortest possible length of time consistent with effective medical care.

3) Public health education may be of considerable value in helping to alter erroneous attitudes held by communities and patients. However, the emphasis must be on education, not propaganda, and the program must be developed by specialists in mass communication. Moreover, efforts at public health education which are inconsistent with medical and paramedical practices in managing the leprosy problem will be counter-productive. For example, the community and the patients will most surely be highly skeptical of proclamations that leprosy is only mildly infectious, or that it is a disease like any other, when patients find themselves excluded from general medical facilities.

4) On the other hand, when leprosy is included in comprehensive community health planning and is treated by the same personnel

responsible for prevention and treatment of the community's other major health problems, then the patient and community may truly begin to believe that leprosy is a disease like any other.

5) When health education of the patient and his family, starting at the time of diagnosis, is used as a primary instrument for prevention and treatment of disability, then we are employing a most effective instrument of mental hygiene. The existence of a direct cause-and-effect relationship between prevention of deformity (or management of it once it has occurred) and the mental health of the patient can no longer be denied. These physiological and pathological processes are indeed influenced by the psycho-social influences at work in the patient. When we reach this level of understanding about the complexities of leprosy, only then are we in a position to begin talking about *whole causes* for what may happen to a leprosy patient, and then finally *whole solutions*.

SUMMARY

A stifling smog of ignorance, fear, myth, and superstition surrounds the problem of leprosy, often diminishing the chances for early diagnosis and effective treatment. Furthermore, existing prejudices are apt to exert a strong influence on the patient's own view of himself and his role in society, and to sharply reduce his chances for recovery.

A leprosy patient is often unable to build up a self-identity that will reestablish his feelings of self-respect and integrity. Leprosy institutions are full of persons of this kind. For this and other reasons, an institutionalized patient's ability to regain a useful, creative role in community life and his chances for doing so tend to diminish in direct proportion to the length of time he has been away from his home and community.

Even when the patient is not institutionalized and when his self-identity is not irremediably damaged, the psychological problems that he faces are immense. In any society

where leprosy has opprobrious connotations, he must still perform the following tasks: (1) manage tensions in his relations with others; (2) cope with both facts and uncertainties about the disease; and (3) reconcile differences between his former and present perceptions of himself and his role in society.

While there are no certain solutions for the psycho-social problems of leprosy, a number of positive steps have proven productive. These include a variety of measures to assist the patient's development of a sound mental attitude during diagnosis; a public health approach to leprosy management that permits the person being treated to remain at home; treatment of leprosy cases at general medical facilities rather than special facilities; accurate and carefully thought-out programs of public health education; and health education of the patient and his family aimed at prevention and treatment of the adverse psychological effects of his condition.

BIBLIOGRAPHY

- (1) Gussow, Zachary, and George S. T. Tracy. Stigma and the leprosy phenomenon: The social history of a disease in the nineteenth and twentieth centuries. *Bull Hist Med* 44: 425-449, 1970.
- (2) Gussow, Zachary, and George S. Tracy. Status, ideology, and adaptation to stigmatized illness: A study of leprosy. *Human Organization*. (In press.)
- (3) Gussow, Zachary, E.R. Knight, and M.F. Miller. "A Theory of Leprosy Stigma and Professionalization of the Patient Role: Adaptation to A Chronic and Uncertain Illness." Unpublished paper based on an oral presentation at the One Hundred and Twenty-First Annual Meeting of the American Psychiatric Association held in New York in May 1965.
- (4) Gussow, Zachary, and George S. Tracy. Behavioral research in chronic diseases: A study of leprosy. *J Chronic Dis* 17: 179-189, 1964.
- (5) Ryrie, G.A. The psychology of leprosy. *Lepr Rev* 19: 119-120, 1948.
- (6) Schofield, Frank D. Some relations between social isolation and specific communicable diseases. *Am J Trop Med Hyg* 19: 167-169, 1970.
- (7) Giel, R., and J.N. van Luijk. *Leprosy in Ethiopian Society*. (Privately circulated paper, 1972.)
- (8) Miller, Marvin F. *The Psychiatry of Leprosy*. Paper presented at the Meeting of the Central Neuropsychiatric Association, New Orleans, Louisiana, 1959, pp. 1-6.
- (9) Skinsnes, Olaf K. *Leprosy Rationale*. Leprosy Missions, Inc., 1964, pp. 1-31.

CORRIGENDUM

We wish to advise our readers of two errors in the text of the article "Comprehensive Health Planning in the United States" by José Duarte de Araújo, which appeared in the last issue of the *Bulletin* (Volume VIII, No. 3, pp. 249-257.

In paragraph two of page 254, the name of the author referred to on the tenth line should be spelled "Roseman."

In the last paragraph of the same page, the first sentence should begin as follows: "The question of controversial 'Medi-Cal' (California State Medical Aid Program) reform and its consequences for low-income groups, providers of health care, and county finances was taken up in the Finance Committee. . ."